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## Pine-Richland staffer 'combing the world' to find lifesaving bone marrow match for her son



**TANISHA THOMAS** | Thursday, December 9, 2021 12:01 p.m.

Missy Ramirez has never won the lottery, but she is determined to win the one that will save her 6-year-old son's life.

Ramirez's son, Jax, was diagnosed with IPEX, a rare genetic autoimmune disease, in October. The diagnosis was a relief for Ramirez who worked tirelessly to find answers to her son's Type 1 diabetes diagnosis since 2017. The Type 1 diabetes diagnosis led to other illnesses and spending several days in the PICU.

"I am combing the world looking for my perfect match to save Jax," said Ramirez, a school psychologist in the Pine-Richland School District.

Jax has lived in a "bubble" since his first diagnosis to protect him. He attends online learning through Seneca Valley. When covid hit, Ramirez said it was a blessing and a curse. She was scared of what covid would do to him after seeing how he fought the flu. The possibility of another illness impacting him is what pushed Ramirez to figure out what was affecting her son.

"I needed the answers. I saw what the flu did to him, and I couldn't imagine what covid would do to him," she said.

Ramirez said IPEX is fatal and most kids do not live past 2. The only way to save her son's life is by finding a match for him to receive a bone marrow transplant. The news crushed Ramirez, who said the family has not found a perfect match for their son yet.

"When you hear it's fatal and you have a 6-year-old, it is the worst news a mom could get," she said.

While Ramirez and her husband, Pete, decided to go public about Jax's journey to find a donor, Jax does not know about his condition. His parents wanted to be his warriors and face the challenging journey ahead.

"What we described to him is your doctors think you are a really cool kid who has gone through so many things. You can teach the world what it is like to be Jax Ramirez," she said.

The sudden interest in his story inspired the Zelenople boy to start his own YouTube channel to



COURTESY OF MISSY RAMIREZ

Jax Ramirez

show the world his adventures. He makes sure to include his younger brother, Lincoln, in his new endeavor.

Ramirez has received help from her school colleagues to organize donor drive events to encourage people to get a cheek swab. She said it has been a humbling experience having them in her and Jax's corner.

"You don't realize how much you are loved until something like this happens," she said.

The Pine-Richland Association organized a donor drive event Dec. 8 at the Pine-Richland stadium lobby.



bone marrow transplant.

"We consider Missy family, and we take care of our own," she said.

Sipe said the in-person events are important because only 40% of at-home swab kits are returned to find a match.

Ramirez said those interested in helping to find a match can register by texting "JAX" to 61474 or through [my.bethematch.org](https://my.bethematch.org). Those who register must be between the ages of 18 to 40. The swab takes no more than 30 seconds.

Participants do not have to be from the Pittsburgh area. A perfect match will be flown out from anywhere to conduct the bone marrow transplant for Jax, Ramirez said.

"At the end of the day I want to be able to lie down on my pillow and say I did everything humanly possible to be able to help him," she said.

## DETAILS

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### Upcoming donor drives

**Dec. 27:** The Chadwick, Wexford hosted by IHeart Radio

**Jan. 25:** Slippery Rock University student center, second floor, all day

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